



Multiple Sclerosis Society

June 2013

Factsheet

Education for children affected by MS - a factsheet for students, teachers and parents

This factsheet covers education in England, Wales and Northern Ireland. We have a separate factsheet for Scotland - see our website or contact MS Society Scotland: msscotland@mssociety.org.uk or telephone 0131 335 4050.

MS and education

Going to school can be difficult for any child, but for a child with MS it can be even more challenging. 'Invisible' symptoms such as fatigue or pain can be particularly difficult to manage. Cognitive issues - difficulties with attention and memory - could cause problems in the classroom and during exams. In addition, your child's schooling may be interrupted by relapses or medical appointments.

The law governing special needs at school is wide-ranging and complex. We do not go into detail about it in this factsheet, but you can find out more from some of the organisations and sources listed at the end.

How can I help my child?

If your child is already attending school, it is important to talk to the school as soon as possible about any health issues your child is facing. This could well be before an official diagnosis of MS.

If your child has already been diagnosed before applying for a school, you may want to have the conversation before or during the application process. Schools vary in their approach and some may suit your child better than others. Physical environment and distance from home can also play a big part in how easily your child manages - particularly if mobility or fatigue is an issue.

Some children with special needs have a 'Statement', but not all. See the section on Special Educational Needs on page 3 for more information about Statements.

Who do I talk to?

All schools have a designated member of staff who looks after students with any special need. They are usually known as a Special Educational Needs Coordinator (SENCO) or Inclusion Officer or, in Wales, as an Additional Learning Needs Coordinator. As well as making contact with them, it may be a good idea to talk to the head teacher. A letter to the head of the school from your child's MS specialist can also be extremely helpful to highlight their needs.

The important thing is to establish good communication with the SENCO and other teaching staff, so that issues can be resolved quickly when they come up. These will be different for every child with MS, and it's not possible for us to cover all the issues that might arise, but we can give you a general guide, with signposts to other organisations that can offer further information.

Being open to discussing the effects of MS with your child and how it affects their life is also important - it is a three-way conversation.

What are a student's rights in the education system?

There are regulations in place to help people access their education in the best way for them. They are contained mostly within:

(England and Wales) Education Act 1996, the Equality Act 2010 and SEN Education (Special Educational Needs) (England) (Consolidation) Regulations 2001

(Northern Ireland) Disability Discrimination Order and Special Educational Needs and Disability (Northern Ireland) Order 2005.

People with MS are automatically covered by the Equality Act and the Disability Discrimination Order from the moment they are diagnosed

The legislation supports the rights of disabled people and emphasises the legal duty on schools and colleges to make reasonable adjustments to help a student continue their education and not be disadvantaged.

Some examples of reasonable adjustments:

- ▲ parents having input on where a student sits
- ▲ minimising distractions in the classroom
- ▲ monitoring levels of attention and engagement
- ▲ using a tape or digital recorder for recording classes and notes
- ▲ special arrangements for doing exams (see page 5)

There are national minimum standards of education for students who can't attend school because they are ill or injured. These are outlined in guidance called *Access to education for children and young people with medical needs*.

You can get a copy for free from the Department for Education or the Welsh Government (see page 9).

Inclusion

Schools must do their best to provide what's needed for any student who has special needs. They must ensure that a student can join in activities wherever practical.

The school should include parents in discussions and decisions about a student and should also try to get the student's views. Perhaps extra help, a different way of teaching or special equipment is required.

Special educational needs (SEN)

Under the law, special education provision has to be made available for any child with a learning difficulty caused by 'a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age'.

In pre-school settings, this help is called Early Years Action or Early Years Action Plus. At primary and

secondary school it is usually called School Action (SA) or School Action Plus (SA+).

Together, SA and SA+ are known as the school-based stages. Most schools will provide an Individual Education Plan (IEP) to outline targets for the student and how they will be supported. This should be reviewed regularly.

Statement of Special Educational Needs

If the school is unable to provide the help your child needs through SA or SA+, you or the school can ask the local authority (or Education and Library Board in Northern Ireland) to carry out a Statutory Assessment of Special Educational Needs.

The resulting Statement of Special Educational Needs - if it is agreed - means that the school will receive extra funding to offer more support to your child. The process gives an opportunity for professionals associated with your child to provide reports detailing their needs. There is a strict timetable and the resulting Statement is a legal document which describes all the child's needs and special help requirements. With the local authority's support, the school usually provides this. The Statement is reviewed annually, and parents will be invited to take part in review meetings. It could be removed if circumstances change and it is no longer required.

For more information see www.gov.uk for their guide: *Special educational needs (SEN): a guide for parents and carers - revised 2009*. IPSEA also has more information about Statements (see page 10).

The Statement usually lasts until the end of compulsory schooling at age 16, unless the student stays at school, for example in the sixth form, in which case it continues until they are 19 years old.

Once students leave school to continue their education elsewhere, for example at a college or university, arrangements for support are completely different. For more information contact Disability Rights UK (see page 10).

The law governing Statements is likely to change in 2014 with the enactment of the Children and Families Bill 2013. See the Department of Education website for more information.

Special arrangements for exams

Ask the SENCO about special arrangements for exams. The SENCO should help liaise with the exams officer on behalf of the student. The exams officer is responsible for liaising externally with the exam body, putting adjustments in place and generally making sure centres are accessible. Here are some examples of adjustments that could be made:

- ▲ making use of a quiet, distraction-free environment when completing tests
 - ▲ supervised rest breaks during exams
 - ▲ extra time to complete tests
 - ▲ the use of multiple choice tests
 - ▲ dictating answers to a scribe who writes them down, or being allowed to use a computer
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Managing absence

You should let the school know if it becomes clear that your child will be away from school for a substantial amount of time for health reasons. This is especially important if they are likely to be off school for more than three weeks. In this case, you should also notify the local authority.

If your child cannot go to school for 15 working days, the local authority will try to provide them with as normal an education as an illness allows. This might mean, for example, arranging access to home teaching, a hospital school, a hospital teaching service, or an integrated hospital and home education service. The local authority should also have a written policy setting out how it will meet its responsibilities.

Getting back to school after being away for a long time can be daunting, so you may want to encourage your child to stay in contact with their friends - for example, through visits or chatting online - and let them know that they're coming back to school. They might also want to catch up with school friends ahead of time if they haven't seen each other for a while.

When coming back to school after an absence your child may need to choose lessons that they like most to start with, to help them concentrate.

Taking medication at school

If your child needs to have access to their medication at school, talk to the head teacher about it as soon as possible. They will be able to explain what support is available.

This issue should be covered in the school's health and safety policy. If there is a need to clarify exactly what the school can do, they may suggest drawing up a health care plan.

School staff aren't obliged to help a student manage their medication (unless they are employed to do it, for example, as a health care assistant). But staff who volunteer to do so should get the proper training. Schools are advised to consult medical professionals on these issues and might take a cautious approach, seeking full guidance before deciding on a plan. The NHS website has more information - see the information on long term conditions at:
www.nhs.uk/livewell/yourchildatschool

Information for schools

The Department for Education has produced guidance for schools on developing a health care plan and ensuring parental agreement. See the information on managing medicines on their website:
www.education.gov.uk/schools/pupilsupport/pastoralcare

Another website with useful resources for schools is the joint charity project Medical Conditions at School:
www.medicalconditionsatschool.org.uk

Getting to school

Local authorities can provide transport for children with special needs. The rules governing provision of transport to school are complex, however, and depend on many factors including walking distance, safety, family income and the individual needs of the child. Transport needs may well fall within a Statement, in which case the local authority is obliged to meet them. Contact a Family has more information (see page 10).

Social care services also have the power to pay for transport to and from school. Other potential sources of funding for travel might be a school or college discretionary support fund or a charitable trust such as the Snowdon Trust (see page 11).

How can schools help?

Schools can support students with MS by:

- ▲ having a policy and a person responsible for supporting students who are unable to go to school because of medical needs.
 - ▲ making sure all those who help provide education for the student have proper information about their needs and capabilities - and have a programme of work to follow.
 - ▲ providing support to help students re-integrate at school after an illness.
 - ▲ ensuring that the student is kept informed about school social events and after-school clubs.
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How can teachers help?

Teachers can help support students with MS by:

- ▲ educating themselves about the issues that a student with MS could face in school so that they can give them the assistance they need.
- ▲ learning about MS through resources like the MS Society booklet, *What is MS?*

There are other resources available from the MS Society and other charities which help explain MS to different age groups (see 'Read more' on page 11).

With your child's permission, a teacher might want to do something in their class or school to highlight the issues people with MS face. They should always discuss it with you and your child first.

How can the local authority (or Northern Ireland Department for Education) help?

It should be able to help in the following ways:

- ▲ It can ensure that children have access to education from the start, if it's clear that they will be away from school for long or recurring periods.
- ▲ It can ensure that children receive an education of similar quality to that available in school.
- ▲ It can ensure that children get their minimum entitlement of five hours teaching per week if they're educated at home because of illness, as long as their health permits it. For more information go to www.education.gov.uk and search 'medical conditions'.

- ▲ It can ensure that young people with MS are not prevented from attending school because of transport difficulties.

Who else can help?

In England and Wales, the National Parent Partnership Network (NPPN) can help with supporting a student, including resolving disagreements about the education of students with special educational needs. See page 11 for details.

In particular, they can help to find out:

- ▲ whether an assessment should be carried out
- ▲ what special needs the student or young person has
- ▲ how those needs can best be met
- ▲ which school the young person should attend

In Northern Ireland, you should speak to your local Education and Library Board about support available to resolve disagreements.

Moving on to college, university or training

Your child's Statement will come to an end when they leave school, so the school should arrange a transition meeting (in practice, this is often at the time of the annual review). It will involve your child and you, teachers and other relevant professionals, and the outcome is to set out what your child would like to do in the future.

The local authority will also have to carry out a Section 139a Learning Difficulty Assessment (LDA). This is a comprehensive report on the support needed by the student to ensure they can succeed in post-16 education or training, or higher education.

A student recently diagnosed with MS, or with deteriorating health, should also be able to request an LDA, even if they do not have a Statement.

Other sources of information

Read more about the Equality Act on the Equality and Human Rights Commission website
www.equalityhumanrights.com

Read more about the Disability Discrimination Order at
www.nidirect.gov.uk

Government

Department for Education (England)

www.education.gov.uk

0370 000 2288

Welsh Government

English language: 0300 060 3300 or 0845 010 3300

Welsh language: 0300 060 4400 or 0845 010 4400

www.wales.gov.uk

Department of Education Northern Ireland

www.deni.gov.uk

028 9127 9279

Special educational needs – for parents and guardians

England: www.gov.uk/children-with-special-educational-needs/overview

Wales:

www.wales.gov.uk/topics/educationandskills/publications/guidance/senforparents/?lang=en

Northern Ireland: www.deni.gov.uk/index/support-and-development-2/special_educational_needs_pg.htm

Special educational needs – for schools

England:

www.education.gov.uk/schools/pupilsupport

Wales:

wales.gov.uk/topics/educationandskills/schoolshome/pupilsupport/inclusionpupilsupportguidance/?lang=en

Northern Ireland: www.deni.gov.uk/index/support-and-development-2/special_educational_needs_pg/special_needs-code_of_practice_pg.htm

Ofsted

Inspects and regulates to achieve excellence in the care of children and young people, and in education and skills for learners of all ages.

Telephone: 0300 123 4234

www.ofsted.gov.uk

Tribunals – to appeal a decision

Parents whose children have special educational needs can appeal through a tribunal against decisions made by their Local Education Authority or Education and Library Board.

England: <http://www.justice.gov.uk/tribunals/send>
Telephone: 01325 392760

Wales: www.sentw.gov.uk
Telephone: 01597 829800

Northern Ireland: www.education-support.org.uk/parents/special-education/sendist (or contact your local Education and Library Board).

Contact a Family

Charity which supports the families of disabled children, including a special educational needs advice service.

www.cafamily.org.uk
Telephone: 0808 808 3555

Disability Rights UK

Disability Rights UK can give advice on post-16 education, training and employment issues for disabled people.

Disabled Student Helpline: 0800 328 5050
(Tuesday 11.30am-1.30pm and Thursday 1.30pm-3.30pm)

www.disabilityrightsuk.org

IPSEA (Independent Parental Special Education Advice)

National charity providing free advice to families who have children with special educational needs, particularly those with Statements.

Advice Line: 0800 018 4016
www.ipsea.org.uk

Snowdon Trust

Charity that assists physically and sensory disabled people to access vocational and academic courses in the UK by awarding grants.

Telephone: 01403 732 899

www.snowdontrust.org

The National Parent Partnership Network (NPPN)

The Network supports all parent partnership services across England. Parent Partnership Services (PPS) offer advice and support to parents and carers of children and young people with special educational needs.

0207 843 6058

www.parentpartnership.org.uk

Together Trust

A charity operating in the North of England and North Wales which provides care, education, support and improved life opportunities for young people in need.

0161 283 4848

www.togethertrust.org.uk

Read more

The MS Society has a huge range of information online and in free booklets, including:

Childhood MS - a guide for parents

What is MS?

Annie and Dan talk about MS - A YouTube video with puppets explaining MS for ages 0-5 years.

Living with the effects of MS

YoungMS.org.uk

A website dedicated to children and teenagers who either have MS or who are affected by MS.

www.youngms.org.uk

Other useful publications

Department for Education/ Welsh Government booklet:

Access to Education for children and young people with medical needs.

This booklet is written for schools and local authorities, but might be useful for parents and guardians too. It covers many topics including school attendance, what happens if a student is in hospital, successful reintegration into school, partnership with parents and students and continuity of educational provision.

Disability Rights UK has a range of publications for students wishing to go on to further or higher education

www.disabilityrightsuk.org

The National MS Society (USA) produces:

Keep S'myelin

A colourful, engaging, informative and reassuring newsletter for parents and children from the MS Society in the USA. Available online.

www.nationalmssociety.org

References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge). Contact the UK Information Team, or visit www.mssociety.org.uk/library

Can you spare five minutes to help us to improve our information? If so, go to mssociety.org.uk/publications and click on 'Take the survey'

Further copies of this factsheet or other MS Society information

Download from www.mssociety.org.uk

If you don't have access to a printer and would like a printed version of this factsheet, or any other MS Society publication or DVD, call the Information Team on 020 8438 0799 (weekdays, 9am-4pm) or email infoteam@mssociety.org.uk

MS Helpline

The MS Helpline offers confidential emotional support and information to anyone affected by MS, including family, friends, carers, newly diagnosed or those who have lived with the condition for many years. Calls can be made in over 150 different languages, via an interpreter. Call freephone 0808 800 8000 (weekdays 9am-9pm, except bank holidays) or email helpline@mssociety.org.uk

Authors and contributors

Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. The law and government regulations may change. Be sure to seek local advice from the sources listed.

Suggestions for improvement in future editions are welcomed. Please send them to infoteam@mssociety.org.uk

Edited by Amber Hammill and James Bailey

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